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Suspension phenomenon: end-of-life care-seeking behavior of patients

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Abstract: The “suspension phenomenon” describes terminally ill patients caught in limbo within the end-of-life care system, uncertain where to seek appropriate treatment. While Western literature has problematized the binary of home vs. hospital deaths, such framing remains underexplored in Asian contexts. We aim to examine how and why patients and families in China make decisions about the place of end-of-life care and death, and to identify the barriers and facilitators that shape access to different care settings, using qualitative content analysis of death narratives. Semi-structured interviews were conducted with 225 bereaved family caregivers across multiple sites in China, using a Voluntary Cooperative Network Research approach that mobilized multidisciplinary volunteer researchers. Six decision-making approaches were identified: respecting patient preference, pursuing survival, resisting medical authority, prioritizing symptom relief, fulfilling filial duty, and consulting informal medical networks. Seven barriers contributed to suspension: mistrust in local services, financial hardship, facility rejection, inadequate palliative provision, non-disclosure to patients, dilemmas around medical technologies, and COVID-19 disruptions. Five care-seeking patterns emerged: aggressive rescue, intensive caregiving, returning home to die, treatment abandonment, and pursuit of a “good death.” Findings challenge normative assumptions about place of death, revealing how sociocultural, economic and technological factors shape end-of-life trajectories in contemporary China.

Keywords: end-of-life care; place of death; caregiver; terminal care; qualitative study

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Introduction

Patient care-seeking behavior over short periods reflects underlying needs for medical resources, with the decision-making process shaping the transition between different levels of care within the healthcare hierarchy [1]. Previous research on end-of-life healthcare-seeking behavior in mainland China found that patients with advanced cancer experience higher rates of uncontrolled moderate to severe pain, hospitalization, and intensive treatments, with lower utilization of palliative care and hospice services [2]. End-of-life care delivery should be guided by an understanding of where deaths occur to optimize care provision [3]. Although home is perceived as the preferred place of death [4, 5] and the phenomenon of going home to die was validated nation-widely in China [6], above 90 % of the death certificates recorded medical visit history [7]. Limited research was available on how patients and families reach a decision on place of care and death.

TU Jiong, in her work “In Search of a ‘Good Death’: A Sociology Study of Dying, Death and Hospice Care in Contemporary China” [8], elucidated the phenomenon of “unmoored or displaced death” of advanced cancer patients in the Chinese healthcare system using hospital ethnography [9], identifying the inadequate capacity of primary healthcare institutions, limited accessibility of tertiary hospitals, transformation challenges in secondary hospitals, poor coordination across healthcare levels, and geographic disparities in healthcare service availability as the barriers contributed to patient’s quandary for the place of care and death at the terminal life stage. However, Tu’s conclusions may be limited to the perspective of healthcare providers, without accounting for the perspectives of family caregivers – an important proxy group in academic research on care-seeking behavior, which can contribute to an increase in professional awareness of the experiences of dying individuals and assist many in their efforts to understand and support a dying person.

Suspension, or Xuanfu (悬浮) in Chinese, is a concept introduced by Professor XIANG Biao to describe a condition where individuals experience frequent mobility, engage in intensive labor, and disrupt their daily routines. This state is characterized by a temporary pause, aimed at swiftly achieving short-term benefits, before returning to normalcy

[10]. In XIANG's research, he mentioned, "Most citizens must save money to cope with the rising costs of housing, education, and healthcare. 'We work ourselves to the bone to make money now,' a vegetable vendor told me, 'So that we can use that money to buy life (pay for necessary healthcare) later.' If one must 'buy life' in the future, then one must 'sell life' in the present – whenever the opportunity arises." In other words, the focus on accumulating wealth in the present is often perceived to ensure access to life-saving medical resources in the future. He likened the Chinese people to hummingbirds, "vibrating their wings to suspend themselves in the air," a metaphor illustrating how individuals in Chinese society often lack deep reflection on the present. Instead, their actions are oriented toward achieving future goals [11].

During our fieldwork at a tertiary hospital-based palliative care center in Beijing, we observed that terminally ill patients frequently changed their place of care. They often sought multiple consultations across various hospitals, undergoing repeated tests to confirm their diagnosis and to pursue the most effective treatments. This pattern reflects a state of suspension within the end-of-life medical care system, as patients and family caregivers face uncertainty about where to receive appropriate end-of-life care. This sense of suspension is not only shaped by the patients themselves but is also deeply influenced by the structure and dynamics of the Chinese healthcare system. We find that the suspension phenomenon in healthcare seeking at the end of life shares similarities with XIANG's concept, particularly in terms of frequent mobility, intensive treatment [2, 12], and the expectation of a quick resolution. This paper aims to explore the reasons behind the suspension phenomenon experienced by Chinese patients at the end of life.

Methods

Study design

This research is based on a larger study titled "Research on Diverse Models of Hospice Care in China" [2, 12, 13]. This mixed-methods project involved the collection of both quantitative and qualitative data, including over 1,000 quality-of-death questionnaires and nearly 500 death narratives. The death narratives were gathered through interviews with healthcare professionals (e.g., doctors, nurses, social workers, hospice volunteers) and bereaved family caregivers (FCGs) or other knowledgeable informants (e.g., relatives, friends, neighbors) of deceased patients. The semi-structured interviews with FCGs explored personal

information about both the FCG and the decedent, the circumstances surrounding the decedent's final illness, end-of-life care, dying and death experiences, and the FCG's caregiving experiences. Two research questions guided this qualitative study: (1) What was the place of death? and (2) Could you describe the end-of-life care process for the patient?

Population and setting

Bereaved family caregivers were invited to participate in the study [14]. The decedents had received end-of-life care across a range of settings, including home, hospital (tertiary, secondary, and primary levels hospital, acute hospital, village clinic, and traditional Chinese medicine hospital), nursing home, and care home. The sample encompassed decedents from 26 provinces across China.

Sampling and eligibility criteria

This research employed the Voluntary Cooperative Network Research (VCNR) method to recruit participants [13, 15, 16], a pro bono collaborative approach where researchers and volunteers jointly pursued academic objectives, collected data, conducted analyses, and disseminated findings. Travel expenses were the only compensation provided. Research leaders expanded the network by recruiting and training volunteers through social connections. Volunteer researchers were required to meet specific inclusion criteria: (1) a bachelor's degree and coursework in qualitative research methods; (2) interest in and comfort discussing death and end-of-life issues; and (3) completion of three training sessions (6 h) covering death narratives, interview techniques, and narrative reporting.

Data collection

Data were collected over 2 years (2021–2023). A review of the texts revealed that 225 of the 251 narratives from FCGs contained information on decision-making process in place of end-of-life care, while the remainder did not address this topic. Eligible FCGs were primary informants with detailed knowledge of the decedents' diagnosis, prognosis, care-seeking process, place of death and dying and death experiences. For example, during the 2021 research phase, the principal investigator recruited five researchers to lead six sub-groups, who in turn enlisted 70 volunteers from fields such as sociology, anthropology, and health economics. This effort ultimately involved 209 voluntary researchers conducting interviews on end-of-life care, leveraging their networks to recruit participants across diverse demographics.

Submitted reports were reviewed, and those failing quality standards were excluded. Following training, volunteers identified participants and scheduled in-person interviews. Conducted in Mandarin, interviews averaged 30 min, ranging from 20 min to several hours.

Ethical considerations

Ethics approval was obtained from the Internal Review Board of University Research Center. The interview guide was developed with input from an expert panel (Supplementary 1). The consent process included (1) informed consent, where participants were introduced to the study and provided verbal consent; (2) clarification of interview objectives, focusing on the impact of palliative care and hospice services on alleviating suffering, medical decisions during end-of-life stages, and family caregiving burdens; and (3) confidentiality assurances, including anonymization, non-disclosure of real names, and secure data storage. Interviews were conducted after participants confirmed their understanding and consent. Given the topic's sensitive nature, the training emphasized empathetic questioning and flexibility to respect participants' emotional states. No time constraints were imposed, and participants were free to skip questions, with interviews guided by their preferences. Audio recordings were anonymized, transcribed, and securely stored to ensure confidentiality.

Data analysis

The transcripts were analyzed to focus on understanding FCG's perspectives in decision-making processes. Conventional content analysis captures and describes participants' experiences of a phenomenon, thereby situating it within the broader domain of phenomenological qualitative research [17]. Informed by Hsieh and Shannon's guidelines [18], first, the transcribed interviews were read through to get a general feel for the content and thrust of each interview. Next, each interview was read again with attention to the end-of-life care decision-making, with highlighted text that appeared to describe the barriers to seeking end-of-life care, and codes were developed for each identified unit of meaning. The initial coding scheme included primary codes for capturing key factors of the decision-making on place of end-of-life care and death (home, hospital, hospice, etc.) and its barriers in receiving end-of-life care. Working definitions for each code were formulated and then grouped into clusters of related meaning to develop categories. Each category was also defined to achieve a more precise understanding of its

specific meaning in relation to other categories. Exemplars were identified to elucidate each category.

Results

Patient's characteristics

This paper included 225 family caregivers (FCGs) of deceased patients, of whom 62.2 % were the patient's next of kin. Most deceased individuals were aged 60 years or older (76.9 %), male (60.4 %), residing in rural areas (67.6 %), living in first-class economic zones (64.0 %), engaged in farming occupations (50.7 %), and died at home (71.6 %). Advanced cancer was the most common diagnosis, accounting for 45.8 % of cases. Only 5.3 % of the patients received palliative care and hospice services (Table 1).

Analysis of FCGs' accounts revealed three core categories: (1) the decision-making process on the place of end-of-life care and death, (2) factors contributing to the suspension phenomenon, and (3) the pattern of care-seeking behavior reached.

The decision-making process

According to FCGs' death narratives, discussions about the location of patient care and death involved patients, family members, physicians, and acquaintances with medical expertise. In cases of sudden death, no discussions about care and death took place during the decision-making process. Decisions regarding the place of care and death were classified into six distinct approaches: respecting the patient's preferences, pursuing hope for survival, challenging medical expertise and declining intensive treatments, prioritizing relief from suffering, fulfilling filial obligations, and consulting acquaintances with medical expertise.

By respecting the patient's wishes

We observed a significant proportion of patients who wish to die at home at the end of life. FCGs typically make unremitting efforts to ensure that the patient can return home.

When her condition worsened, she (mother) requested to return home, and Mr. Jiang (son) brought her back late at night to ensure she could pass away in familiar surroundings. (Carer 009)

However, while patients expressed a preference to die at home, it was not always the place where they received care and ultimately died.

Table 1: Sociodemographic of the decedents.

	Residential zone	
	Rural (n = 152)	Urban (n = 73)
Age		
18–34	1.3 %	5.5 %
35–59	23.7 %	13.7 %
60 and above	75.0 %	80.8 %
Gender		
Male	59.2 %	63.0 %
Female	40.8 %	37.0 %
Cause of death		
Cardio- and cerebro-vascular diseases	19.7 %	15.1 %
Advanced cancer	45.4 %	46.6 %
Other ^a	34.9 %	38.4 %
Occupation		
Farmer	73.7 %	2.7 %
Other ^b	26.3 %	97.3 %
Relationship to decedents		
Spouse	14.5 %	9.6 %
Children and grandchildren	59.9 %	67.1 %
Other ^c	25.7 %	23.3 %
Place of death		
Home	83.6 %	46.6 %
Hospital	15.8 %	46.6 %
Intensive care unit	1.0 %	1.0 %
Hospice	0.7 %	1.4 %
Care home	0.0 %	1.4 %
Palliative care utilization		
Yes	0.7 %	15.1 %
No	99.3 %	84.9 %
Area ^d		
First class	62.5 %	67.1 %
Second class	26.3 %	31.5 %
Third class	11.2 %	1.4 %

^aOther causes of death include cardiovascular disease, cerebral hemorrhage, dementia, diabetes, falls, liver cirrhosis, stroke, suicide and natural death. ^bOther occupations include captain, journalist, manager, healthcare professional, sales, scientist, self/unemployed, businessman, carpenter, civil servant, and housewife. ^cOther participants who were caregivers of the descent include bother, nephew, daughter in law. ^dThe class of the area was grouped according to the first-level minimum wage standard in 2024 of the province where the patients lived. The first-class area includes Shanghai, Jiangsu, Zhejiang, Beijing, Guangdong, Tianjin, Inner Mongolia, Hubei, Hebei, and Shandong; The second-class area includes Shanxi, Jilin, Liaoning, Henan, Hunan, Chongqing, Sichuan, Xizang, Heilongjiang, Yunnan, and Anhui; The third class includes Ningxia, Fujian, Gansu, Hainan, Jiangxi, Guangxi, Shanxi, Xinjiang, Guizhou, and Qinghai.

Grandma Li disliked hospitals. She feared not the noise of crying or shouting patients but the loneliness of being apart from her family and the possibility of dying alone. Feeling slightly better, she secretly had her granddaughter arrange her

discharge. Initially happy at home, her condition quickly deteriorated, requiring a ventilator. The family bought one for 15,000 yuan but struggled with its poor performance and loud noise, leaving the caregiver sleepless and eventually ill. After a week of exhausting round-the-clock care by her three children and two grandchildren, returning to the hospital became inevitable. (Carer 008)

For some patients, home is not the preferred place to die. They pursue intensive treatments until the very end, ultimately passing away in the hospital.

Ms. Han, a patient with advanced liver cancer, was singularly focused on a cure, insisting on intensive treatment without making after-life arrangements “I must pursue active treatment!” she insisted, reflecting her strong desire for survival. She underwent surgical resection and transarterial chemoembolization. However, the treatments caused severe pain, significantly reduced her quality of life, and left her often fearful and despondent. These struggles weakened her resolve and adherence to follow-up care, ultimately hindering her recovery. Ms. Han died in the hospital. (Carer 018)

Some patients experience repeated indecision and inner conflict when choosing their place of end-of-life care, with frequent changes in their preferred location. A typical example of this is reflected in the decision of whether to be admitted to the ICU.

Grandfather Han had grown weary of life and missed his late wife. When his daughter first asked if he wanted to be admitted to the ICU if his condition worsened, he firmly declined, wanting to spend his remaining time with his children. However, after 10 days in a regular ward, his condition worsened. When asked again if he would consider the ICU, he agreed, asking his daughter, “Will I get better if I go?” She replied, “Yes, you will.” What Grandfather Han didn’t know was that the ICU doctor had told his children there was only a 20% chance of improvement. Despite the low odds, his children chose to take the chance, hoping for their father’s survival. (Carer 012)

By pursuing hope for survival

During the end-of-life stage, patients and their families often opt for intensive treatments in the hope of achieving a marginal chance of survival or extending life. Such interventions may include intensive care unit (ICU) admission, surgery, or dialysis. The outcomes of these treatments are highly individualized, with success contingent on numerous factors. Decisions regarding their initiation may be driven directly by the patient or, in many instances, made by family members on the patient’s behalf.

Despite his growing disillusionment with life, Han chose to go to the ICU, moved by his children’s deep attachment. He hoped a ward transfer might offer a chance at survival. However, after 28 days in the ICU, he had to say a final goodbye. His daughter

later revealed that, midway through his treatment, the family had discussed transferring him out of the ICU, but doing so would have meant giving up on the last chance for treatment – a choice to let him die. She couldn't bring herself to make that decision. (Carer 012)

In some cases, family members pursue intensive treatments with a “last-resort” mindset, viewing such interventions as either a potential gateway to survival or, if unsuccessful, a means to alleviate the patient's suffering.

My mother was in the advanced stages of renal cancer, and her primary physician, my close friend, warned that the success rate for tumor removal surgery was extremely low, with a high likelihood she wouldn't survive. No hospital would risk such a procedure on a late-stage cancer patient, but I was determined to pursue it, clinging to even the slimmest hope. I insisted, promising, “Our family will assume all risks and won't hold the doctors accountable.” Though I hadn't yet discussed it with my mother, my friend empathized, saying, “If successful, she might gain a few more months. If not, it could end her suffering.” I shared everything with my mother, and she, as always, trusted my decision completely, embodying the deep love and bond we shared. Against all odds, a miracle happened. The surgery succeeded, and the doctor credited her optimism. I felt profoundly grateful for her strength and my unwavering determination. (Carer 016)

However, such decisions may result in the premature death of patients who could have otherwise lived with their illness for an extended period, albeit with some compromise in quality of life, due to the risks associated with intensive treatments.

87-year-old Mr. Jin fractured his right femoral head after a nighttime fall at home. Hospital surgeons recommended a hip replacement to prevent long-term bed confinement but insisted on pre-operative dialysis to mitigate the risk of intraoperative kidney failure and death, despite the family's concerns about its risks. Mr. Jin underwent dialysis and the hip replacement, but less than 12 hours after surgery, he suffered cardiac arrest. Doctors attempted resuscitation without the family's consent, but their efforts failed. The family had agreed to the surgery, believing it offered a slim chance of recovery over the inevitability of being bedridden. Resolute by nature, Mr. Jin immediately consented, unwilling to accept a life of immobility. (Carer 175)

By challenging medical expertise and declining intensive treatments

We observed an obvious trend of patients and families willing to die at home challenging the physician's expertise.

After more than 10 days of hospitalization in the county, my grandfather resisted the hospital environment, refusing preoperative tests, food, and medication, expressing only a desire to return home quickly. (Carer 099)

Meanwhile, going home to die is related to refusing intensive treatment.

The doctor recommended tracheal intubation, but Grandfather Huang's family declined, perceiving it as a sign of impending death. After further discussion, the attending physician agreed to forgo the procedure, choosing instead to monitor his condition for two days to allow for potential improvement and transfer to a general ward. Ten days later, he was discharged and returned home. (Carer 1)

When family members witness the patient's suffering, are unable to accompany them, and face communication difficulties with medical staff, being offered unclear or ambiguous treatment plans, they often question the doctors' professionalism after the patient's death. They may also experience self-blame, regret, and grief over what they perceive as mistakes in their decision-making.

The pain was compounded by the poor communication between Jiayan and the doctors during her father's critical, life-and-death decisions. As a medical professional, she felt the treatment in the ICU lacked transparency, and they could not fully understand her father's condition. She longed to be with him but was unable to visit due to ICU restrictions. Jiayan repeatedly expressed regret, saying, “He suffered, and I couldn't be there.” She often wondered if taking him out of the ICU would have changed the outcome. She even questioned whether her father resented them for not taking him out, not visiting, or curing him. (Carer 012)

By prioritizing relief from suffering

When family members learn that a patient has an irreversible illness, minimizing suffering often becomes their primary goal and guiding principle in end-of-life care. This objective shapes decisions regarding the patient's treatment plan, place of care, and location of death.

Ms. Nan's maternal family had a history of cancer, with two close relatives suffering painful deaths from the disease. When her mother was diagnosed with cancer, despite having no prior knowledge of palliative care, Ms. Nan and her father adopted “minimizing suffering” as the guiding principle throughout her treatment journey. Her mother spent her final days in the palliative care unit at S Hospital, passing away peacefully. (Carer 148)

When families prioritize the patient's quality of life over life extension and opt for hospice as the place of death, hospital procedures – such as signing do-not-resuscitate directives – can impose a significant moral burden on them.

We signed directives for “no resuscitation, no intubation, and no artificial cardiac support,” but with each shift change, the attending doctor required all four of us to re-sign. Their disbelief

in our decision, coupled with direct questions like “Are you really not going to save them?” placed immense moral pressure on me, making me doubt our choice. (Carer 159)

By fulfilling filial piety

For family members, especially children, filial piety often means doing everything within their power to care for the patient and providing the best possible medical care.

My father was already 86 years old, and all the children had fulfilled their duty of filial piety by staying by his side. In the end, we did everything we could to save him, but when nothing more could be done, we were deeply saddened yet mentally prepared. We came to accept his passing with a sense of peace. (Carer 149)

I believe that fulfilling filial piety first requires capability. I've come to realize that being able to afford a medication costing ¥50,000 a month is a privilege that only a small minority can achieve. (Carer 148)

Yet often, things do not go as hoped, leading to the regret that “children wish to care, but the parents are no longer there.”

Mr. Jiang recognized his mother's lifelong sacrifices, from arduous farm work and household chores to caring for grandchildren and supporting his home renovation. He hoped improved finances and his child's graduation would allow her to rest and for him to provide more care. Tragically, her diagnosis of advanced oesophageal cancer shattered these plans. He now regrets missing early signs, delaying intervention, and neglecting her well-being. (Carer 009)

By consulting acquaintances with medical expertise

Acquaintances with medical expertise frequently appeared in the death narratives as trusted individuals known to FCGs. They played a pivotal role in securing hospital beds, advising on critical medical decisions such as *extracorporeal membrane oxygenation* (ECMO), resuscitation, tube feeding, surgery, dialysis, ventilation, and facilitating ICU admissions, where FCGs often faced restricted access. Their guidance significantly influenced the place of end-of-life care and death.

As COVID-19 intensified, stricter restrictions and the need for daily hospitalization made managing his care increasingly challenging. Concerned about bed availability and admission protocols, we sought another hospital where, through connections with acquaintances, we secured a private room. (Carer 005)

Yan's father called a trusted doctor friend, who advised against ECMO, citing its painful nature and low success rate. (Carer 002)

However, acquaintances are not always reliable, and their recommendations can sometimes mislead overwhelmed families seeking urgent solutions. In some cases, such

suggestions may delay treatment and worsen the patient's condition.

During Beijing's COVID-19 pandemic, strained medical resources made securing a hospital bed without connections nearly impossible. Following an acquaintance's recommendation, the family consulted a “celebrity physician” at B Hospital, whose indifferent care and restrictive treatment delayed effective care by half a month. (Carer 030)

Factors contributing to the suspension phenomenon regarding place of end-of-life care and death

We identified six factors contributing to the “suspension phenomenon” concerning the place of care and death for patients at the end of life: doubts about the quality of care in local hospitals, financial constraints, rejection by healthcare facilities, inadequate palliative care and hospice services, concealing information from patients, issues related to medical technology, and challenges associated with COVID-19 (Figure 1).

Questioning the quality of local hospital care

When patients lack trust or confidence in the medical care standards of local hospitals, receiving end-of-life care at home becomes a compromise. In such cases, patients may opt to purchase medication on their own and manage symptoms at home.

Grandfather Huang was relatively stubborn and refused to go to the hospital, believing that the local hospital in Huangqiao (town) was entirely unreliable. As a result, he self-administered erythromycin at home for an entire year. (Carer 001)

When local healthcare facilities, especially in rural areas, lack the capacity to provide home visits, accessing medical care becomes increasingly difficult for patients. Consequently, patients are often forced to make frequent, long-distance trips for treatment.

The village health station is rarely visited and does not offer home visits. We seldom go there for medical treatment. The level of medical modernization and services at the village health station does not meet our expectations. People tend to prefer going to larger hospitals instead. (Carer 224)

Constrained by financial burden

Patients with malignant tumors often transfer between multiple hospitals to confirm a consistent diagnosis before coming to terms with their condition. Following diagnosis, they frequently travel between home and hospitals for treatment. Constrained by financial circumstances, patients and

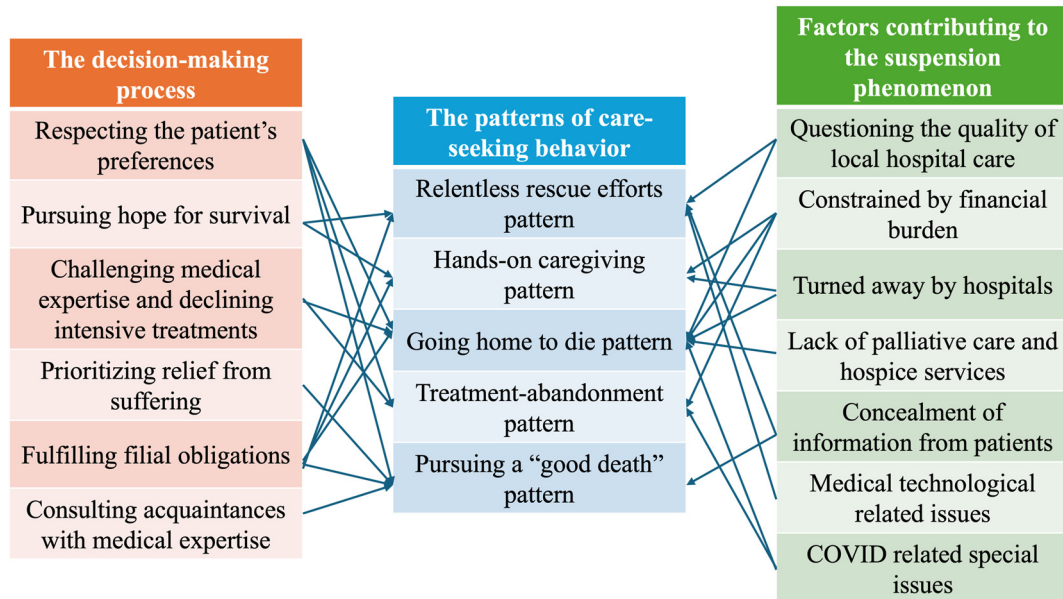


Figure 1: Conceptual model illustrating the interplay between decision-making, suspension dynamics, and end-of-life care-seeking behaviors.

their families strive to gather funds to sustain care. Once they exhaust their resources, they often return home to die.

Uncle Li spent over 200,000 yuan on colorectal cancer treatment, with nearly half covered by the rural cooperative medical insurance. The remaining 150,000 yuan was jointly covered by Uncle Li, Sister Yang, and her aunt, without borrowing from others. Over five years, except for hospital stays in Shenyang, he convalesced at home, staying active with daily tasks to earn a living. He appeared healthy to outsiders, with only his family aware of his illness. Shenyang, where he sought treatment, was the farthest Uncle Li had ever traveled. The city's bustling life felt distant, serving only as a place to seek care. (Carer 007)

Ning, a 20-year-old girl, cared for her father, Mr. Zhan, a 51-year-old with advanced lung cancer. Four years earlier, he had suffered a stroke at 47, exhausting the family's savings. Now facing a terminal illness, he could no longer seek hospital treatment – partly because he refused to go and partly because the family couldn't afford it. In his final days, Mr. Zhan was cared for at home, with Ning seeking local clinic doctors to visit and administer intravenous fluids. (Carer 025)

However, some patients' families may go to great lengths, even incurring debt or selling property, to provide the best possible care.

We borrowed over 100,000 yuan from relatives and friends because our family couldn't afford the costs alone. Initially, everyone pitched in, but later, when we asked for more, they either ignored us or said they had no money to lend. With the debt still unpaid, maintaining those family relationships has become impossible. (Carer 225)

Turned away by hospitals

In China, end-of-life patients and their families often seek care from multiple providers, moving between hospitals of varying levels. Top-tier tertiary public hospitals, or “major” hospitals, are viewed as the best for definitive diagnoses and treatments. However, these hospitals primarily focus on rare and complex diseases, making them less suitable for common cancers. Nonetheless, for many desperate families, they symbolize hope and reflect distrust in local healthcare services.

In April, Shuxia, concerned about limited local medical resources, took her mother to tertiary Z Hospital, where gastric cancer was suspected but not confirmed. In May, she transferred her mother to the Gastroenterology Department of a higher-level C Hospital. Despite over ten days of hospitalization and pathological tests, a diagnosis remained unclear, though surgery was recommended. Shuxia, aware that “total immunohistochemistry” could confirm cancer, disagreed with the attending physician's insistence on diagnostic gastrectomy. In July, she sought care at Beijing's 301 Hospital (one of the top hospitals in China), where physicians advised that cancer treatments were largely uniform and recommended continuing care locally.” (Carer 013)

We had previously visited the county hospital, but due to the complexity of the illness, they eventually refused to admit the patient, saying the condition was severe and untreatable. This led us to seek care at the city hospital. (Carer 206)

When terminal patients forgo specific treatment options, they may find themselves without access to care due to a mismatch between their preferences and the standard

treatments offered by most hospitals. This may partly result from strict health insurance coverage based on evidence-based medical pathways, which limit treatment options, but it could also stem from families' limited understanding of palliative care.

Because we refused chemotherapy and radiotherapy, few hospitals were willing to admit my mom as a patient. I later learned that radiotherapy is also a form of palliative care. After undergoing radiotherapy, her symptoms were significantly relieved. (Carer 148)

Lack of palliative care and hospice services

We found that only 5.3 % of the patients in the sample received palliative care or hospice services. The lack of these services may result in terminally ill patients experiencing severe pain and symptoms without access to appropriate care settings, ultimately dying without peace and dignity.

No known local medical institutions were offering palliative care services. From diagnosis to death, grandfather stayed at home. Whenever he felt unwell, he would go to the community hospital for intravenous infusions, mostly immunoglobulin to boost his immune system, with no other treatment measures. As for cancer pain, the family did not take any action or consider pain management, partly because grandfather rarely complained and did not want to burden the family. Most of the time, he simply endured the pain. (Carer 010)

In certain regions, public hospitals have yet to provide palliative care services, whereas private hospitals offer such services but frequently lack the necessary qualifications to ensure quality. By 2023, the national pilot program for hospice care had expanded to 185 pilot cities (or districts) [19]. A total of 4,259 healthcare institutions had established palliative care departments, predominantly in tertiary and secondary hospitals located in developed regions [20].

She considered transferring her father to a hospice facility but decided against it. In her city, there were no public hospices, only private ones, which she felt lacked the necessary care and facilities. As a medical professional, she did not believe these private institutions could meet the standards she expected for her father's end-of-life care, so she chose not to transfer him. (Carer 012)

In some cases, patients are aware of palliative care services but are unable to access them due to accessibility-related barriers such as distance and lack of insurance coverage.

Lisa was aware of the palliative care unit at C Hospital, but the long distance from their home in Xicheng District and the lack of insurance coverage made the costs prohibitively high, leading them to forgo this option. (Carer 030)

Concealment of information from patients

Concealment of information from patients can serve as a latent contributor to the suspension phenomenon. When patients are unaware of their diagnosis, prognosis, and medication treatment, they may normalize their pain and develop a high tolerance for discomfort, not realizing that pain can be effectively managed through medical intervention. As a result, they may delay or forgo seeking care in a palliative care and hospice setting, potentially missing the opportunity for timely treatment.

In 2018, my father was diagnosed with lung cancer. He was only hospitalized in the final stages. Given his age, we chose to conceal the severity of his condition and opted for conservative treatment. On many occasions, he optimistically told us, "It's nothing serious; I'll be fine with treatment." He never expressed any pain, only mentioning a "burning" sensation in his stomach. After five years, we still believed that not telling him the truth at the beginning was the right decision. He was a person who overthought, and had we told him, he might not have been able to bear the psychological burden." (Carer 005)

Concealing a diagnosis may lead to discrepancies between the treatment setting and the illness as described to the patient. However, evidence on the extent to which such concealment impacts a patient's ability to receive care in their preferred location remains limited.

Her father, Mr. Li, was diagnosed with gallbladder and prostate cancer. Until his passing, neither his family nor his doctors disclosed the cancer diagnosis to him, attributing his condition instead to "cholecystitis" and its complications. Even his admission to the oncology ward was explained as a result of a lack of available beds elsewhere. (Carer 030)

Medical technological related issues

The inadequacy of medical equipment poses significant challenges to maintaining patient care in a home setting.

As Grandfather Huang's condition worsened, marked by persistent coughing, Xiao Chen, his son-in-law, retrieved an oxygen concentrator from a relative, but its low flow rendered it ineffective. After Huang's return from the ICU, a neighbor offered the family a nearly new hospital-grade adjustable care bed, previously used by the neighbor's late mother. Xiao Chen set up the bed at home, and the family later acquired a high-flow oxygen concentrator online. These adaptations extended Grandfather Huang's life by half a year. (Carer 001)

Transfers between hospitals are often necessitated by inadequacies in medical equipment, which can subject vulnerable patients and their caregivers to additional strain and potentially unfavorable outcomes.

Initially, Mother took Grandfather to B Hospital, but the doctors there indicated that their equipment was insufficiently advanced to manage his condition and recommended transferring him to the E Hospital, which had more advanced facilities. Upon arrival, the doctor advised, “Prepare for the worst,” and proposed a cardiac stimulant – if effective, treatment would continue; if not, they would cease efforts. Aware of Grandfather’s advanced age, Mother agreed. That afternoon, Grandfather passed away. (Carer 003)

COVID-related special issues

During the pandemic, staffing shortages, lack of critical medications, and restrictive regulations left patients and families overwhelmed, resulting in significant chaos and burden.

My grandfather’s recovery from COVID-19 was incomplete, and he subsequently developed a fever due to a secondary infection. The hospital, overwhelmed by a surge in cases, faced staff shortages and lacked essential medications such as immunoglobulin. With no available caregivers, my parents took turns staying overnight, but my father fell ill, leaving my mother to manage caregiving alone. Amid this crisis, the medical staff, already stretched thin, were unable to address my grandfather’s fever. (Carer 002)

Mr. Ming said, “At that time (refer to COVID-19), no hospital was willing to admit an elderly patient.” (Carer 008)

The patterns of care-seeking behavior

Five patterns of care-seeking behavior were observed: relentless rescue efforts, hands-on caregiving, returning home to die, abandoning treatment, and striving for a “good death.”

Relentless rescue efforts pattern (全力救治型)

Adequate financial support, stable economic conditions, and advanced health insurance coverage reduce the occurrence of suspension phenomena, allowing patients to seek care at places preferred by their families. However, whether these localities align with patients’ preferences remains uncertain.

That night, Yan was informed that Grandfather’s oxygen levels had dropped dangerously, and he was unresponsive. After signing consent, he was transferred to the ICU. The next day, the doctor reported his worsening condition and inquired about ECMO, urging the family to prepare for the worst. Determined to pursue life-sustaining treatment regardless of the cost, the family was willing to sell their property if necessary. While Yan and her father had personal savings, Grandfather’s access to decent healthcare insurance for retired cadre alleviated financial concerns. (Carer 002)

We just wanted her to live one more day (in the ICU), to feel better for one more day. A cure would have been ideal, but if not, at least she could have one more day. (Carer 018)

Hands-on caregiving pattern (亲力亲为行)

Family caregivers may take on caregiving responsibilities far beyond their capacity, sometimes at the expense of their well-being, careers, families, lives, and health. They frequently distrust other caregivers, healthcare providers, and long-term care facilities, preferring to shoulder the burden themselves. This practice of bringing elderly family members home for care reflects a deep-rooted adherence to the Confucian value of filial piety in Chinese culture.

Hong Yi, a nurse with a thriving career and a happy family, became the sole caregiver for her parents after her father’s stroke and her mother’s chronic illnesses for several years. Refusing to place them in a nursing home, she brought them into her home, resigning from work and closing her clinic to provide full-time care. This devotion came at great personal cost, as she neglected her own family and health, eventually developing schizophrenia and later advanced rectal cancer, which led to her death at the age of 55. (Carer 039)

In some contexts, family caregivers become actively involved in the medical care of patients. Beyond distrust in external caregivers’ ability to provide dedicated care, economic considerations also drive families to assume caregiving responsibilities themselves.

His parents were concerned about the cost of hiring a caregiver, and his mother was particularly reluctant to entrust his grandfather’s care to outsiders, fearing less attentiveness and potential conflicts. With the Chinese New Year approaching and caregiver fees prohibitively high, she decided to take on the caregiving role herself. However, the prolonged effort in the hospital eventually took a toll on her health. (Carer 003)

Going home to die pattern (落叶归根型)

Going home to die symbolizes a return to one’s roots, ensuring the individual does not pass away “without a sense of belonging” in an unfamiliar place. It is a common practice for families to bring patients home when they are on the brink of death, allowing them to spend their final moments surrounded by loved ones and in the comfort of their own homes.

When Mrs. Jiang’s (mother) condition worsened, she requested to return home, and Mr. Jiang (son) brought her back late at night to ensure she could pass away in familiar surroundings. (Carer 009)

At times, a patient’s sudden death may prevent the realization of their wish to return home, leaving family members with unresolved regret and, in some cases, prolonged grief.

Mr. Tian passed away suddenly before he could be discharged from the hospital to return home. His unfulfilled wish to go home left his daughter with deep regret during his final moments, a regret that later led to prolonged and unresolved grief. (Carer 029)

Treatment-abandonment pattern (放弃治疗型)

Some patients may actively request to discontinue treatment and return home during the end-of-life stage, not wanting their illness to continue burdening their loved ones.

G, an 80-year-old hemophiliac, suffered frequent bleeding episodes as his condition worsened, receiving multiple emergency visits and blood transfusions, which drained both him and his family. G repeatedly emphasized his desire to leave the hospital and pass away at home. The niece, the primary decision-maker for G's treatment, said that G might be aware of his condition and didn't want to burden them. She added that she didn't want him to suffer before his passing either, so they had signed a do-not-resuscitate order. (Carer 019)

For some patients, their desire to forgo treatment may not stem from a true wish to stop care but rather from inadequate pain and symptom management. This leads to a phenomenon described as “dying for relief, striving to survive.” When physical pain becomes unbearable, they may seek to abandon treatment in favor of a swift death. However, when their symptoms improve, newfound hope often emerges, prompting them to continue treatment.

Pursuing a “good death” pattern (追求善终型)

For some patients, dying with dignity entails minimizing suffering, alleviating the financial burden on families, and being freed from the pain caused by medical interventions, while respecting and accepting the nature of dying and death.

Xia Shan believed that quality of life and dignity should never be compromised. He felt medical devices not only failed to improve life but prolonged suffering, diminished dignity, and burdened families financially. Therefore, Xia Shan refused invasive ventilator support, hoping his family would respect his wish to die with dignity and end his pain. (Carer 110)

The intervention of palliative care and hospice teams helps fulfill the patient's wishes, ensuring a peaceful and dignified end-of-life experience.

The family reported to the social worker, “We fulfilled the elderly person's wish to pass away at home, surrounded by his closest loved ones.” (Carer 019)

Discussion

The derived model (Figure 1) depicts the interrelation between the decision-making process, factors related to the suspension phenomenon, and end-of-life care-seeking behavior patterns. Patients often receive relentless rescue efforts driven by their hope for survival, influenced by the strong filial piety of family caregivers, particularly next

of kin. Study show that caregivers tend to opt for more intensive care when making end-of-life decisions on behalf of the patients [12]. Rural patients, distrusting local hospital care, may seek treatment in urban or high-reputation tertiary hospitals to improve survival. However, financial constraints, limited insurance, or lack of family support may prevent access to such care. In the pursuit of filial piety, caregivers may conceal information from patients to alleviate their fear of dying, while advanced technologies offer hope for life prolongation.

FCGs are pivotal in end-of-life care, especially when care is delivered at home, often motivated by filial piety and a deep commitment to the well-being of their loved ones. However, limitations such as financial constraints and denial of admission to healthcare facilities have led FCGs to assume greater responsibility for hands-on caregiving. Research has highlighted that FCGs play a crucial role in administering medication to dying patients at home, often without adequate support from healthcare professionals [13]. Going home to die often occurs when they question the quality of care in local hospitals, particularly in rural areas, and seek to alleviate financial and caregiving burdens on family caregivers, while attempts to access care in higher-level hospitals are often met with refusals or limited access to palliative and hospice services. Patients' wishes to die at home were more often respected by family members in rural areas than in urban settings in this study. However, further research is needed to conduct a comparative analysis of urban-rural differences in the extent to which patients' wishes to die at home are respected.

Patients often abandon or refuse medical treatment due to financial constraints. These decisions are particularly associated with discontinuing life-prolonging intensive treatments, especially when patients are reliant on life-sustaining machines, as they prefer to alleviate suffering rather than live as a medical “cyborg.” Restrictive regulations during the COVID-19 pandemic hindered patients' access to end-of-life care in hospitals and also limited healthcare professionals' ability to provide home-based care. Respecting a patient's wish to alleviate suffering and die at home supports the pursuit of a “good death.” In these circumstances, family members often conceal information about the diagnosis and prognosis to mitigate the patient's mental burden and sustain hope for survival. However, caregivers may experience a profound conflict between fulfilling filial obligations and signing do-not-resuscitate orders, which may be due to the lack of involvement of palliative care specialists.

Several factors identified in this study have not been as prominently featured in previous research on patients'

end-of-life experiences [21–23] or decision-making [24–26]. Patients and families often distrust intensive treatment plans proposed by healthcare institutions, turning instead to familiar relatives and friends with medical expertise for guidance. These trusted individuals typically recommend forgoing futile interventions. This skepticism may stem from concerns about physicians' financial motives, the perceived lack of emotional warmth in healthcare, or doubts about the quality of care the institution provides, with the belief that better resources may be accessible through personal connections. At times, familiar individuals can offer more reliable healthcare information, alleviating the burden on patients and families who may otherwise struggle to navigate a complex healthcare system with limited direction. Family members may see intensive treatment as a last effort to prolong life, even with minimal chances of success, viewing death as the end of suffering. This may result from healthcare institutions not offering alternatives, such as palliative or hospice care, between intensive treatment and death.

The suspension of patients within the end-of-life healthcare system is closely linked to China's social and cultural context. Over the past 40 years, two dominant value systems – social control and the promotion of financial success – have shaped Chinese society [10], rendering the process of achieving cognitive transformation both challenging and arduous. The suspended state of life, akin to that of a hummingbird, may extend into the end of life, simultaneously affecting family members at the end of life. As illustrated by the case of Mr. Jiang mentioned earlier, he was preoccupied with his own life and allowed his mother to bear the burden of living. Despite being aware of her deteriorating health, he did not intervene early, which ultimately delayed her treatment and left him with deep regret. Previous research has identified filial piety as a protective mechanism within a healthcare system marked by significant public distrust [22]. However, filial piety may conflict with the values of palliative and hospice care, which prioritize alleviating pain and suffering without pursuing life prolongation through intensive care. For those who uphold filial piety, the emphasis is often on providing the best possible care, regardless of the financial or caregiving costs.

Although China has established a comprehensive medical insurance system, the economic constraints faced by terminally ill patients in accessing healthcare remain a concern. Palliative care should be integrated into the essential healthcare system and covered by universal health insurance as a form of free medical service [27]. However, in China, palliative care is currently regarded as a luxury. On one hand, its availability is limited; on the other hand, it is

prohibitively expensive. A study on the costs of palliative care in Beijing for patients with malignant tumors found that medical expenses for those receiving palliative care during the last six months of life amounted to ¥39,518, with an average hospital stay of 12.32 days [28]. In 2023, the Beijing's per capita disposable income was ¥81,752, with urban residents earning ¥88,650 and rural residents ¥37,358 [29]. According to the China Statistical Yearbook, in 2023, 60 % of the national population had an annual *per capita* disposable income of less than ¥32,195 in China [30]. Currently, China is exploring the inclusion of palliative care services within the national health insurance system.

The overuse of intensive treatment at the terminal stage is often overlooked in China. Dr. Luo Diandian's research found that about 80 % of China's healthcare expenditures are allocated to end-of-life artificial life-support systems each year. To maximize economic gains, hospitals at all levels in China have developed ICUs.¹ Artificial life-support systems do not impose a significant financial burden on many publicly insured patients from China's privileged class. However, for the general public, hospitals' repeated inquiries about forgoing life-saving interventions place surrogate decision-makers under intense financial pressure and moral strain, as they balance economic costs with the hope for a loved one's survival. Dr. Luo Diandian advocates for reallocating end-of-life care funding and resources, suggesting that medical resources currently allocated to intensive treatment should be redirected toward preventing curable diseases.

Western developed countries' healthcare policies, like those in the United Kingdom, encourage more patients to die at home [14, 31]. China has a unique foundation for achieving home deaths, with traditional beliefs such as “falling leaves return to the root” and families' emphasis on filial piety, where caregivers often provide hands-on care. However, current palliative care policies in China are hospital-centered rather than community- and family-based [19]. This situation may be attributed to the seven factors discussed in this paper that contribute to the suspension phenomenon. Patients and families are not receiving adequate end-of-life care at home or in the community, and the “patient-centered” healthcare model does not fully address the needs and vulnerabilities of terminal patients. As a result, patients frequently transition between different healthcare settings, rather than receiving integrated care tailored to their needs. Future research should explore how

¹ The data are sourced from the CCTV-1 program Seeing (Episode 20130325), titled ‘Choice and Dignity’. <https://v.qq.com/x/page/d0331yb2sxf.html>.

to shift medical resources to the home and community to promote the development of home-based palliative care.

This study has several limitations. First, it is subject to the typical constraints of retrospective research involving bereaved caregivers, who may cope with their loss by constructing subjective narratives. Second, the study primarily explores the factors contributing to the suspension phenomenon, which acts as a barrier to healthcare-seeking across various end-of-life care settings, with relatively less emphasis on the facilitators. Future research should investigate the positive factors that facilitate access to or delivery of care for patients at the end of life. Third, inspired by Xiang Biao's seminal work on suspension, this paper mainly provides explanations of the financial constraint dimensions of displaced care. Further studies should examine how the suspension phenomenon impacts death and dying among Chinese patients. Fourth, although we identified financial factors as a key barrier to accessing quality end-of-life care, further quantitative research is needed to determine the extent of their impact. Despite these limitations, this study distinguishes itself by addressing end-of-life decision-making, challenges, and healthcare-seeking behaviors across diverse settings, including homes, hospitals (general wards and ICUs), and palliative care institutions. It also includes patients with a range of diagnoses, offering insights into their choices regarding healthcare location and place of death.

In conclusion, this paper offers the first in-depth examination of the decision-making process among patients and family members seeking end-of-life care across various settings. The process was influenced by a range of interrelated factors, leading to a distinct suspension phenomenon and resulting in diverse patterns of healthcare-seeking behavior. The findings have significant clinical implications, highlighting the need for healthcare professionals to better empower family caregivers by providing adequate support. Additionally, the results offer insights for healthcare policymakers to enhance the delivery of home-based palliative care and optimize the allocation of medical resources.

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